



## **NEWBORN SCREENING WORKGROUP MEETING NOTES**

THURSDAY, JULY 16, 2009

8AM – 11AM

DENVER, CO

**CO-CHAIRS: JEFF BOTKIN & SUSAN TANKSLEY**

### **Discussion on July 15<sup>th</sup> MSGRCC Project Presentations**

Requirements of grantees:

- Reporting of data is an issue for this region to NNSGRC
- ACHDNC needs data set from states
- States have to report to get block grant funds
- Clearinghouse will pull together a group
  - Need exact definitions for what data the clearinghouse is seeking
- NNSGRC can send out help
- **ACTION ITEM:** Need to meet about this for 2009 date
- Region 4 has come to agreement on case definition.
  - Michelle Puryear has contact for bridge.
  - **ACTION ITEM:** Celia to send email.
- Clearinghouse (3 applications were received) will be awarded on September 1.
- HRSA needs data (report to Congress on 2012)
- NSIS will be part of clearinghouse; it will not be a new database system.
- Texas is recording data, not from funding, from infrastructure.

Emergency Preparedness Workgroup meeting update, held on July 15<sup>th</sup> – Donna Williams, chair, will be sending out a survey for preparedness assessment.

Residual specimens issues:

- doctor, or birth attendant, must disclose to parent
- Form on the website if the parent objects.
- NBS kit will contain the disclosure of specimens.
- Relates to Botkin's NIH project which is studying regionally and nationally attitudes toward newborn screening residual specimen usage.

- **ACTION ITEM:** Email out date of the ACHDNC in September (23<sup>rd</sup> or 24<sup>th</sup>) on open dialogue in Washington.

## State Updates

### TEXAS

- CF to be added (one of the last states to add. Only other state is CT).
- December 1: IRT/IRT/DNA
- All secondary targets now mandated but not funded, also adds NBS Advisory Committee.
- Working with New England on SCID grant (10,000 babies 1<sup>st</sup> year); grant submitted for LSD
- New CAH kit being validated
- Will change to new non-derivitized PerkinElmer kit, which contains succinylacetone
- Another bill passed that requires disclosure to families that specimen may be retained and used for public health purposes and gives the families the right to opt out of the storage and use of the residual blood spots. Another bill mandates to screen for sickle trait.
- SS Act has Medicaid set aside for counseling; no state is currently doing this.
- Remote data systems – providers can request NBS reports online and enter demographic information for NBS tests online. Over 500 providers are enrolled so far and allows up front data entry when samples are collected (prints labels).
- NBS Performance Measures Project: Have formed a stakeholder team (includes insurance company representative, parent, providers, Brad, Erica, Cheryl, Lois Taylor, others representing the NBS system) and are developing evidence-based performance measures focused on improved outcomes in children with NBS disorders.
- Educational initiatives:
  - UTSW will be affiliated with Dell Children's in Austin.
  - Internal education initiative for Public Health staff.

### UTAH

- CF now going, as of January 1, terminology incomplete verses abnormal)
- CH now TSH (seeing a lot of TSH < 1)
- New projects:
  - Communication about false positives (looking for funding).
  - Prenatal educational tools at 36 weeks
  - Question and Answer Report Card
- Will stop treating Duarte's
- Succinylacetone now in primary screen
- CDC second tier grant still pending

### MONTANA

- No new conditions
- No advisory committee

- Model of education – doing staff education in PCP offices when child developed
- 1<sup>st</sup> metabolic day for families

### OREGON

- No new tests
- May change HB screening method
- Neometrix update (HL7) will contain case management, remote data entry

### NEW MEXICO

- Screens for 26 disorders
- No new ones
- STF6 nurse in Oregon
- All Hb traits to SS council
- Challenge is database implementation (linked to EHDI, etc.)

### NEVADA

- Personnel changes, no one has primary NBS job
- Looking to take back NBS program

### COLORADO

- LSD's have caught attention of legislators
- E-reports and web access, data entry coming soon
- No SSA yet
- Increase fee to pay for courier
- F1U program ???

### WYOMING

- Contracts out all lab services
- Hiring freeze
- Needs NBS metabolic Advisory Committee
- No in-house data collection system

### ARIZONA

- Budget issues
- MOD / Jim Kelly changed appropriation around
- CAH validation
- Primary TSH since May 4
- New MS will re-evaluate all cut-offs
- Data reporting is the biggest challenge
- Data integration is non-existent but a work in progress
- Development of an educational position for both internal and external

### Presentation #1

## Presentation #2

Next steps / Action Items: Susan Tanksley concluded the meeting by thanking the states for the updates and thanking the speakers for their presentations.

Action items discussed were:

- Email out date of the ACHDNC in September (23<sup>rd</sup> or 24<sup>th</sup>) on open dialogue in Washington.
- Post presentations to the web-site
- Email announcement of next meeting date, time & location when the meeting is scheduled.

Meeting adjourned at 11:10am.